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The Forgotten Rights of Donor Offspring



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Like adopted children, those conceived through a donor should have a legal right to access personal information about their biological parents.

Olivia Pratten, a young woman conceived by donor sperm nearly 30 years ago, wants to know her biological father – her **bio-dad**. Pratten believes that Dr. Gerald Korn, the physician who inseminated her mother, has information that could help her in her quest. Korn, however, claims that the file with the donor information has been destroyed, so it can't be shared with Pratten. He also says that confidentiality in the doctor-patient relationship prevents him from disclosing any information about a patient.

Even if the relevant file has been destroyed, it's possible that Korn remembers information that could be helpful to Pratten. His assertion that he can't disclose any information to Pratten is presumptive, as it depends on whether this information exists in medical files or in his head. The matter is now before the courts.

But Pratten isn't fighting merely in her own interest; she's arguing on behalf of all donor-conceived children for the right to access personal information (including health information) about their progenitors (including sperm, egg, or embryo donors). This would require the creation of permanent records – presumably in some kind of registry – to avoid the possible destruction of relevant information.

The Canadian Medical Association's Code of Ethics mandates that physicians protect the personal health information of their patients. The code also specifies that a physician may disclose such information to others only with the patient's consent or when required to do so by law.

Currently, Canadian law as entrenched in the Assisted Human Reproduction Act of 2004 requires the collection of personal health information about sperm, egg, or embryo donors. This information may not be disclosed for any purpose, except with the written consent of the donor or in accordance with stipulated disclosure requirements outlined in regulations (these regulations have yet to be developed). As only health information (not personal information) is to be collected, however, the anonymity of donors is thereby protected in law.

In medicine, the promise of confidentiality has practical benefits: it promotes full and honest disclosure by patients, and it facilitates a sense of trust between physicians and patients. Both of these measures are necessary for physicians to properly treat patients.

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In contemporary ethics, the promise of confidentiality is grounded in the commitment to respect patient autonomy. Autonomous patients have the right to control their own personal information and to decide who will have access to it. Furthermore, physicians have a duty to prevent – or at least minimize – harm to their patients, and a breach of confidentiality can cause considerable harm.

The promise of confidentiality is not absolute, however. It can be breached if someone is at risk of harm that is serious, unavoidable except by unauthorized disclosure, and proportionate to the harm that would result from the breach of confidentiality.

Donor-conceived children and adults have said repeatedly, and in no uncertain terms, that denying them information about their genetic heritage is harmful to their sense of self and general well-being. Providing these individuals with access to information about the sperm, egg, or embryo donor(s) used to create them would minimize these harms.

As a society, it's important that we take seriously the interests of persons created by assisted human reproduction. If these individuals tell us that entrenching secrecy and protecting the interests of donors over their own interests causes them harm, then the rules need to be changed. In other words, we have to stop promising donor anonymity.

Relevant donor information is released in other countries, including Sweden, Norway, Britain, Switzerland, and Australia. In these countries, prospective donors of reproductive material are informed that at some later time, any child conceived using their sperm, egg, or embryos will have access to their personal information. If prospective donors don't want this, they can choose not to donate, and none of their rights will be violated.

While this approach may solve the problem for future donors and children, it leaves unresolved the claims of donor-conceived children who have already been born of anonymous donors. In this special circumstance, there is reason to respect the original promise, but also to facilitate the meeting of persons with a mutual interest in getting to know each other. Not only are there donor-conceived individuals interested in meeting their progenitors, there are also donors interested in meeting their genetic offspring. We have helped to reunite children of adoption with their birth parents when this is a mutually desired outcome, and there would seem to be no principled reason not to do the same for donor-conceived individuals.

We need to listen carefully to what donor-conceived individuals are telling us. Their lived experience matters.

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